

Family Psychoeducation

Implementation Resource Kit



EVIDENCE-BASED PRACTICES
Shaping Mental Health Services Toward Recovery

DRAFT VERSION
2003

Implementation Resource Kit User's Guide

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Foreword

The Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) is a proud sponsor of this implementation resource kit for Family Psychoeducation. As the federal agency responsible for promoting the quality, availability, and accessibility of services for people with mental illness, CMHS is responsible for identifying treatments for mental illness that work. The materials in this resource kit document the evidence for the effectiveness of Family Psychoeducation and provide detailed information to help communities to implement the practice in real world settings. During development of the implementation resource kit, we placed special emphasis on 1) strengthening the consensus-building process, 2) expanding the involvement of consumers and families, 3) including practical orientation to issues involving service organization and financing, and 4) insisting on paying careful attention to issues of ethnic and cultural sensitivity and overall cultural competence. We are well pleased with the result.

Many other organizations contributed to developing this implementation resource kit. This broad coalition of researchers, providers, administrators, policy makers, consumers and family members, gives the resource kit its strength and vitality. We are especially appreciative of the support provided by The Robert Wood Johnson Foundation that sponsored the early stages of the Project, when evidence-based Family Psychoeducation was identified as a practice ready for widespread implementation. We agreed. This evidence-based practice has been consistently shown to reduce relapse rates of people who have mental illnesses and live with their families. CMHS has found the role of family members to be vital for assuring quality care for many consumers. Family psychoeducation is a proven way to engage family members, to relieve family tensions regarding mental illness, and to improve outcomes for consumers.

This implementation resource kit reflects the current state-of-the-art concerning evidence-based Family Psychoeducation. It addresses both the "key ingredients" of the clinical model and many practical considerations essential for successful implementation. It also describes the need for each community to adapt the model to its particular needs and characteristics. Careful attention to unique community needs, coupled with fidelity to the key ingredients of the practice, equals successful implementation. The closer the kit user comes to following the implementation resource kit guidance, the more likely the practice will yield good results for consumers.

As mental health services research and evaluation progress, CMHS hopes to support the development of implementation resource kits for additional evidence-based practices, and to refine this and other previously-developed resource kits to take new evidence into account. Indeed, evaluation of planned pilot projects for implementing this resource kit and associated implementation strategies will tell us much about how to make improvements in future versions. We hope that this

and other evidence-based practice implementation resource kits will be helpful to communities across the nation as they strive to provide the most effective services possible for persons suffering from mental illness.

Introduction

Welcome to the Family Psychoeducation implementation resource kit. It has been produced by the Implementing Evidence-Based Practices Project as part of an effort to promote treatment practices in community mental health service settings that are known to be effective in supporting the recovery of adults with severe mental illnesses. The goal: to improve the lives of consumers by increasing the availability of effective mental health services.

The User's Guide begins by providing general information about the Implementing Evidence-Based Practices Project, including the goals and values of the project. This is followed by descriptions of the materials contained in the resource kit and their proposed role in the implementation process. The basic structure of an implementation plan is outlined. Specific suggestions for implementing the practice of Family Psychoeducation are presented in the Implementation Tips documents. This guide also contains a list of annotated references on Family Psychoeducation and a special populations appendix which provides a review of the literature addressing the range of populations for which this practice has demonstrated efficacy or effectiveness.

If you have any questions or comments about these materials or the implementation process, please contact Kristine Knoll at the NH-Dartmouth Psychiatric Research (e-mail address: Kristine.M.Knoll@Dartmouth.EDU). We look forward to supporting your efforts to improve services to people with severe mental illness. Also, please share your experience in using these materials. Feedback from users will help refine and improve future versions of these implementation materials.

Background

What are “evidence-based practices”?

Evidence-based practices are services for people with severe mental illness (consumers) that have demonstrated positive outcomes in multiple research studies.

Over the past 15 years, researchers in mental health service systems have gathered extensive data to support the effectiveness of several psychosocial and pharmacological treatments. In 1998, the Robert Wood Johnson Foundation convened a consensus panel of researchers, clinicians, administrators, consumers, and family advocates to discuss the research and to determine which practices currently demonstrated a strong evidence base. This project is an offshoot of these efforts.

The six evidence-based practices

Six practices were identified as currently demonstrating a strong evidence base:

- ▶ standardized pharmacological treatment
- ▶ illness management and recovery skills
- ▶ supported employment
- ▶ family psychoeducation
- ▶ assertive community treatment
- ▶ integrated dual disorders treatment (substance use and mental illness)

Other evidence-based practices for the treatment of persons with severe mental illnesses are being identified and will be promoted as the research evolves. This project is only a beginning attempt to establish models and procedures. This list of identified practices is not intended to be complete or exclusive. There should be many evidence-based practices in the future. Some promising practices being researched currently include peer support programming, supported housing, trauma services, and treatment for people with borderline personality disorder.

What is an implementation resource kit?

An implementation resource kit is a set of materials—written documents, videotapes, PowerPoint presentations, and a website—that support implementation of a particular treatment practice.

Specific materials in this resource kit have been developed for each of the key stakeholder groups involved in the implementation effort:

- ▶ consumers of mental health services
- ▶ family members and other supporters
- ▶ practitioners and clinical supervisors
- ▶ program leaders of mental health programs
- ▶ public mental health authorities

Research has shown that providing practice guidelines to practitioners alone does not change practice. Change is most likely to occur and be sustained if all the major stakeholders in the mental health system are engaged and involved in the process of change. Therefore the materials and guidelines in this implementation resource kit are geared toward five different stakeholder groups. The materials for each specific stakeholder group were either written by representatives of that group or in close collaboration with them.

The resource kit materials are also designed to address three stages of change:

- ▶ engaging and motivating for change (why do it)
- ▶ developing skills and supports to implement change (how to do it)
- ▶ sustaining the change (how to maintain and extend the gains)

What is an implementation package?

An implementation package is a set of implementation materials (the resource kit) combined with complementary training and consultation that support implementation of the evidence-based practice. The resource kit materials are designed to be most effective when used with consultative and training services. As part of the Implementing Evidence-Based Practices Project, EBP implementation centers are being established in various states across the country to provide consultation and training (see www.mentalhealthpractices.org).

How was this implementation resource kit developed?

A team made up of multiple stakeholders developed each resource kit: researchers, clinicians, program managers and administrators, consumers, and family members. Documents oriented toward specific stakeholder groups were either written by the stakeholders or in close collaboration with them. A consensus panel, also comprised of multiple stakeholders, reviewed the materials developed for all of the six implementation resource kits to ensure consistency of presentation and attention to the various perspectives of the different constituencies.

For more information

For a more detailed discussion of the project and the implementation strategies, refer to the enclosed *Psychiatric Services* articles:

Drake RE, Goldman HH, Leff HS, et al: Implementing evidence-based practices in routine mental health service settings. *Psychiatric Services* 52:179–182, 2001.

Torrey WC, Drake RE, Dixon L, et al: Implementing evidence-based practices for persons with severe mental illnesses. *Psychiatric Services* 52:45–50, 2001.

Project Philosophy and Values

The project rests on two philosophical tenets:

First, mental health services for people with severe mental illnesses should have the goal of helping people to develop high-quality, satisfying functional lives. That is, services should aim not just at helping consumers stay out of the hospital and reducing or stabilizing symptoms, but also at helping them to pursue their own personal recovery process. People want services that help them to manage their illnesses and to move ahead with their lives.

Second, consumers and their families have a right to information about effective treatments, and in areas where evidence-based practices exist, consumers and family members have a right to access effective services.

Evidence-based practices are not intended to be exclusive, mandatory, or rigid. Rather, they imply self-knowledge, self-determination, choice, individualization, and recovery.

Defining recovery

There have been many efforts to define the recovery philosophy. The Consumer Advisory Panel for the Implementing Evidence-Based Practices Project drafted the following brief statement. The principles of recovery that informed the development of the implementation resource kit materials are:

- ▶ hope
- ▶ personal responsibility
- ▶ education
- ▶ self-advocacy
- ▶ support

The cessation of symptoms is not necessarily equal to recovery. Each person develops their own definition of recovery, which many view as a process rather than a destination.

It is important to know what is meant by “support.” While the support of others is a valuable element in recovery, it does not include solving problems for another person or giving advice.

Empowerment is another critical component to recovery. A person becomes disempowered when choices are made for them, even when well-meaning supporters do it. Disempowerment also occurs when assumptions or judgments are made concerning an individual and their choices.

Recovery is most easily achievable when a person and those around them recognize the individual as a whole and complete person regardless of symptoms. One of the most valuable things a person can do for someone with psychiatric symptoms is to listen.

For more information

Copeland, Mary Ellen. *Wellness Recovery Action Plan*. 1997. Peach Press.

Ralph, Ruth O. *Review of Recovery Literature: A Synthesis of a Sample of Recovery Literature 2000*. Report produced for NASMHPD/National Technical Assistance Center for State Mental Health Planning.

Components of the Family Psychoeducation Implementation Resource Kit

The following describes the purpose and content of the individual resource kit materials. This section is followed by a description of the use of these materials in the implementation process.

Implementation resource kit user's guide

This document describes the implementation resource kit and how to use it. It includes annotated references for the particular evidence-based practice.

Introductory videotape

This short videotape functions as an introduction for all stakeholders to the evidence-based practice. Much of the film consists of different stakeholders speaking of their experience or demonstrating the practice in action. A Spanish-language version of this videotape is also available.

www.mentalhealthpractices.org

This website contains basic information about each of the six evidence-based practices. It includes references and links to other relevant websites. Information for consumers and family members is available in Spanish.

Information for stakeholders (five documents)

These documents describe the evidence-based practice and highlight features of the practice most pertinent to the particular stakeholder being addressed. These are engagement pieces that address the question: why should I, as consumer, family member, practitioner, program leader, or administrator be interested in this practice? The documents for consumers and family members are available in Spanish-language versions.

Statement on Cultural Competence

This document addresses the need for practitioners and policymakers to integrate the design and delivery of the evidence-based practices within a culturally responsive context.

Practice demonstration videotapes

These videotapes model clinical skills critical for the implementation of the practice. They are designed for use in training and supervisory settings.

Workbook

The workbook is designed as a primer for practitioners regarding skills needed to provide the evidence-based practice. It emphasizes the knowledge and skill practitioners need in order to provide an effective intervention, one with high fidelity to the model. It is designed for use in training or supervisory settings.

Implementation Tips for Mental Health Program Leaders

This document provides practical guidance for agency program leaders on how to implement the evidence-based practice in a community mental health setting. It includes strategies for building consensus in organizations preparing for change and tips on how to develop policies and procedures to support the practice.

Implementation Tips for Public Mental Health Authorities

This document provides practical guidance for public mental health authorities on how to provide incentives and remove barriers to implementation of the evidence-based practice within their mental health system. Advice is given based on the experiences of mental health systems that have been successful in implementing the practice. This document emphasizes the importance of consensus building, creating incentives for change in practitioner and agency behavior, and identifying and removing barriers to change.

Client outcome measures

Using outcome measures to evaluate and track consumer gains and program success is critical for effective implementation of an evidence-based practice. Simple outcomes are identified that can be monitored as part of routine clinical practice. The tracking of outcome measures is used as a feedback mechanism for clinicians, supervisors, and administrators.

Fidelity scale

Research indicates that the quality of implementation of the practice—adherence to principles of the model—strongly influences outcomes. The fidelity scale enables mental health program leaders to evaluate their program in comparison to the recommended principles.

Articles

Copies of general articles about evidence-based practices and implementation and an article describing the research evidence for this particular practice are included in the implementation resource kit.

Additional implementation materials

PowerPoint presentations are available to supplement the Family Psychoeducation resource kit materials. Contact the West Institute at the New Hampshire-Dartmouth Psychiatric Research Center (603-271-5747).

How to Use the Resource Kit Materials – An Implementation Plan

Effective implementation of evidence-based practices is best achieved by using the materials with a structured complementary consultative and training program. As part of this project, a number of evidence-based practices implementation centers have been established throughout the country. For more information on these centers, go to www.mentalhealthpractices.org.

A brief description of a basic implementation plan that includes these supports is provided below. See the *Implementation Tips for Mental Health Programs Leaders* and *Implementation Tips for Public Mental Health Authorities* for more detailed suggestions regarding the implementation of Family Psychoeducation.

Consensus building

Build support for change

- ▶ identify key stakeholders
- ▶ provide information to all stakeholders
- ▶ develop consensus regarding a vision for the practice at your agency
- ▶ convey a vision and a commitment to all stakeholders

Enthusiasm for the implementation of the evidence-based practice can be generated by communicating how the practice benefits consumers and family members.

Use of implementation resource materials

- ▶ Distribute information materials to the key stakeholder groups.
- ▶ Hold informational meetings with key stakeholder groups. Have opinion leaders within the different stakeholder groups co-host these meetings. Include a viewing of the introductory videotape. An introductory PowerPoint presentation can be used to structure the informational meeting.

Developing an implementation plan

An action plan

- ▶ identify an agency implementation leader
- ▶ establish an implementation steering team that includes representatives from all stakeholder groups
- ▶ secure a consultant from an EBP implementation institute
- ▶ develop an implementation plan

Responsibilities of the implementation leader and implementation steering team include identifying and utilizing personnel, resources, and processes (administrative support and system changes) needed to support the evidence-based practice; an assessment of training needs; and development of an implementation timeline.

Consultants from EBP implementation centers can work with public mental health authorities and program leaders to inform them about the practice, to evaluate an agency's or system's commitment to change, and to assess current realities of financial incentives, staffing, and structure.

By developing partnerships with community organizations including peer support programs, consumer and family advocacy groups, police, homeless shelters, food banks, department of vocational rehabilitation, and others depending on the specific practice, the implementation leader and the implementation steering team can most effectively develop support for the practice. These groups may contribute to the development of an implementation plan.

Use of implementation resource materials

- ▶ *Implementation Tips for Public Mental Health Authorities* is designed for individuals at the municipal, county, or state mental health authority.
- ▶ *Implementation Tips for Mental Health Program Leaders* is designed to be shared with the individuals in an agency that make and carry out decisions about the local resources and processes. This includes people who have responsibility for program management, training, policy development, program standards, data management, and funding.

Enacting the implementation

Making it happen

- ▶ involve agency personnel at all levels to support the implementation
- ▶ host a “kick-off” training where all stakeholders receive information about the practice
- ▶ host a comprehensive skills training for agency personnel who will be providing the practice
- ▶ arrange opportunities to visit programs that have successfully implemented the practice
- ▶ work with an implementation center for off-site support for the practice
- ▶ review current agency outcome measures relative to the practice and modify outcome data to monitor the practice. Learn how to make use of outcome measures in clinical practice and supervision
- ▶ work with a consultant/trainer to learn how to use the fidelity scale to identify strengths and weaknesses in the implementation effort

Trainers can work with the agency to offer an initial or "kickoff" training for all stakeholders. The trainer can then provide comprehensive skills training for those personnel within the agency who will be providing the practice. The trainers may offer to visit the program at least one day per month for the first six months, then one day every other month for the next six months, for ongoing training, consultation, supervision as needed by the program. The trainer may also be available on a weekly basis for phone consultation.

Use of implementation resource materials

Many agencies find it useful for the implementation leader and agency staff to familiarize themselves with the structure and processes of the practice by visiting an existing program. Before a site visit, the implementation leader and clinical supervisor(s) should review:

- ▶ *Information for Practitioners and Clinical Supervisors*
- ▶ *Information for Mental Health Program Leaders*
- ▶ *Implementation Tips for Mental Health Program Leaders*
- ▶ *Workbook for Practitioners and Clinical Supervisors*

Materials that support training and clinical supervision

- ▶ *Workbook for Practitioners and Clinical Supervisors*
- ▶ Practice demonstration videotapes
- ▶ PowerPoint training presentation (available from the West Institute)

Trainers may also serve as consultants to the administrators of the program. This includes demonstrating the usefulness of outcomes data as a clinical feedback tool. See *Monitoring Client Outcomes*.

Monitoring and evaluation

Sustaining change: How to maintain and extend the gains

- ▶ establish a mechanism for continuous feedback regarding how the practice is being provided in an agency
- ▶ publicize outcome improvements from the practice
- ▶ use fidelity scales to monitor the practice implementation

Monitoring and evaluation occur in several ways. First, the use of consultants to provide side-by-side, ongoing consultation during the first one to two years of the program is very helpful. Consultants who are experienced in the practice can recognize problems and recommend changes to address them.

Use of implementation resource materials

It is useful for programs to become comfortable early on with the measures that will be used for monitoring and evaluating the delivery of the practice: outcome measures and the fidelity scale. The information collected can be used not only to identify areas that are problematic, but also to identify areas of excellence. See *General Organizational Index*. Feedback from these measures may be used to promote and strengthen clinical and programmatic effectiveness.

A Word about Terminology

Terms used in the Implementation Resource Kit materials

The materials were developed by people from a variety of backgrounds and perspectives. During development, it became evident that many different terms are used to describe the key stakeholders. For the sake of clarity and consistency, in most instances common terms are used to identify these groups throughout the implementation resource kits. In some situations more precise, or alternative, terminology is used. For instance, in the Supported Employment implementation resource kit, the term ‘employment specialist’ is often used rather than “practitioner.”

Consumers, clients, people who have experienced psychiatric symptoms

These terms refer to persons who are living with severe mental illness and who use professional mental health services—the consumers of mental health services. The term ‘consumer’ is most frequently employed in the resource kit materials. In the Integrated Dual Disorders Treatment workbook and in the outcome measures document, the term ‘client’ is used. The Illness Management and Recovery resource kit uses the term ‘people who have experienced psychiatric symptoms’.

Family and other supporters

This terminology refers to families and other people who provide support to a consumer, and recognizes that many consumers have key supporters who are not family members.

Practitioners and clinical supervisors

The term practitioner refers to the people who deliver the evidence-based practice. This is used instead of clinician, case manager, nurse, psychiatrist, therapist, etc. except when referring to a specific kind of role (e.g., the employment specialist in supported employment, or the prescriber in medication management). The term clinical supervisor is used to distinguish between an administrative supervisor and the person supervising the clinical work of the practitioner.

Mental health program leaders

This term is used to describe the person at the mental health provider organization who is trying to put the practice into effect. This term is used instead of program supervisor, operations director, program manager, or program administrator. The term is used because it makes it clear that this person’s job is to lead with the support of the agency’s administration.

Public mental health authorities

This term is used to describe the people who determine the regulations and funding structures of the public mental health system. We recognize that evidence-based practices are also implemented and overseen in the private sector.

Phases of the Implementing Evidence-Based Practices Project

The Implementing Evidence-Based Practices Project was planned to take place in three phases over a five to six year period, as described below.

Phase I: Development of the Implementation Resource Kits – Fall 2000 to Summer 2002

During Phase I the core principles and critical elements of each of the six evidence-based practices were identified and guidelines for their implementation developed. This resulted in the development of a comprehensive implementation plan – production of implementation resource kits and development of a structured program of training and consultation – to facilitate the adoption of evidence-based practices in routine clinical settings.

Phase II: Pilot Testing the Implementation Resource Kits – Summer 2002 to Summer 2005

Phase II entails a multi-state demonstration of implementation using the resource kit materials in conjunction with a structured program of consultation and training. The goals are (1) to demonstrate that evidence-based practices can be successfully implemented in routine practice settings; (2) to improve the implementation resource kits including the recommendations for consultation and training support based on information gathered from pilot experiences; and (3) to learn more about the range of variables that facilitate or impede implementation in routine treatment settings.

Phase III: National Demonstration – starting in 2006

Phase III is designed to be a broad implementation effort in which the modified implementation resource kits will be made available throughout the United States. Research will focus on both evaluating the success of implementing evidence-based practices and their effects on client outcomes.

Readings and Other Resources on Family Psychoeducation

Essential Readings for Practitioners

The following four books are recommended for those wanting to master this approach. The first includes key elements of the Anderson and Falloon approach and should be read first. The Miklowitz, et al., book is essential for those working with consumers with bipolar disorder.

McFarlane, W.R., **Multifamily Groups in the Treatment of Severe Psychiatric Disorders**, New York, NY, Guilford, 2002.

Anderson, C., Hogarty, G., Reiss, D., **Schizophrenia and the Family**, New York, NY, Guilford Press, 1986.

Falloon, I., Boyd, J., McGill, C., **Family Care of Schizophrenia**, New York, NY, Guilford Press, 1984.

Miklowitz, D.J., Goldstein, M., **Bipolar Disorder: A Family-focused Treatment Approach**, New York, NY, Guilford Press, 1997.

Additional Resources for Practitioners

Amenson, C., **Schizophrenia: A Family Education Curriculum**, Pacific Clinics, 1998.

Provides 150 slides with lecture notes for a class for families with a member with schizophrenia. Includes information about the illness, medication and psychosocial treatments and the role of the family in promoting recovery.

Amenson, C., **Schizophrenia: Family Education Methods**, Pacific Clinics, 1998.

Companion handbook to Schizophrenia: A Family Education Curriculum provides methods for forming a class, optimizing the learning of families, and dealing with typical problems that arise in conducting family classes.

Mueser K, Glynn S, **Behavioral Family Therapy for Psychiatric Disorders**, Oakland, New Harbinger Publications, 1999.

Psychopharmacology

The Essential Guide to Psychiatric Drugs by J. Gorman, St. Martin's Press, 1995.

Written for a sophisticated consumer, it is the most accessible source of information about psychotropic medications. It distills the Physician's Desk Reference into understandable language. It describes the individual "trees" (such as Prozac) in the forest of medicines. "The benzodiazepines: Are they really dangerous?" is a typical section heading.

Medicine and Mental Illness by M. Lickey and B. Gordon, Freeman, 1991.

A scholarly yet readable work written for professionals, it is best at teaching the principles of diagnosis, neurophysiology and psychopharmacological treatment of mental illness. It describes the "forest" of psychopharmacology, why it is there and how it works. "The blockade of dopamine receptors and antipsychotic potency" is a typical section heading. It does not discuss the profiles of individual medications.

Cultural Competence

The Cross-Cultural Practice of Clinical Case Management in Mental Health edited by Peter Manoleas, Haworth Press, 1996.

A collection of useful articles about the role of gender, ethnicity, and acculturation in treatment seeking and response. Provides guidelines for engaging and intervening with specific ethnic and diagnostic groups in varying treatment contexts.

Videotapes

Schizophrenia Explained by William R. McFarlane, M.D. Produced by, and order from, the author at Maine Medical Center, 22 Bramhall Street, Portland, ME 04102. (Phone 207-871-2091) mcfarw@mmc.org.

This provides a full review in lay language of the psychobiology of schizophrenia, emphasizing the key concepts in family psychoeducation: stress reduction, optimal environments and interactions for recovery, and support for the family's ability to contribute to recovery in many ways. It is often used in lieu of a psychiatrist during Family Education Workshops and for staffs of case management programs, community residences and employment programs to help them understand how to assist consumers with this disorder.

Exploring Schizophrenia by Christopher S. Amenson, Ph.D. Produced by the California Alliance for the Mentally Ill (Phone 916-567-0163).

This videotape uses everyday language to describe schizophrenia and give guidelines for coping with illness for persons and their families.

Surviving and Thriving with a Mentally Ill Relative by Christopher Amenson, Ph.D., Third edition 1998.

Eighteen hours of good "home video quality" videotapes cover schizophrenia, bipolar disorder, major depressive disorder, medication, psychosocial rehabilitation, relapse prevention, motivation, and family skills. Order from Paul Burk, 1352 Hidden Springs Lane, Glendora, CA 91740. (Phone 626-335-1307).

Critical Connections: A Schizophrenia Awareness Video, produced by the American Psychiatric Association, 1997.

This 30 minute video was designed by the APA to help consumers and families cope with the disabling effects of schizophrenia. It provides a hopeful, reassuring message about new medications and psychosocial treatments that assist with recovery.

Exploring Bipolar Disorder by Jerome V. Vaccaro, M.D., 1996.

One hour professional quality videotape describes the illness, recovery, and the role of the family. Persons with the illness contribute valuable insights. Produced by and ordered from the California Alliance for the Mentally Ill, 1111 Howe Avenue, Suite 475, Sacramento, CA 95825. Phone 916-567-0163.

Periodicals

Schizophrenia Bulletin: Highly technical and difficult to read but it is the ultimate source for research findings. The fall 1995 issue summarizes "Treatment Outcomes Research".

Psychiatric Services: Practical articles in all aspects of mental illness. Brief clinically relevant articles on medication and other treatments. The most useful periodical for clinical staff.

Psychosocial Rehabilitation: Practical psychosocial rehabilitation articles. Easy to read and understand. Provides "how to" details. Contains good consumer written articles.

Other Resources

There are a number of excellent books written for persons with a mental illness and their families to help them understand and deal with these illnesses. Many of these are helpful for professionals directly and all are important resources to which to refer patients and families. (See Reading List for Families.) Many of the professional and family books are offered at a discount by the National Alliance for the Mentally Ill, 200 N. Glebe Road, Suite 1015, Arlington, VA 22203-3754. Phone: 703-524-7600.

Books on Mood Disorders (Bipolar and Unipolar Depression)

A Brilliant Madness: Living with Manic Depressive Illness by Patty Duke and Gloria Hochman, (Bantam, 1992)

Combines personal experience with clinical information to describe manic depression in understandable terms and provide guidelines for coping with it.

Control Your Depression by Peter Lewinsohn, Ricardo Munoz, Mary Ann Youngren, and Antonette Zeiss, (Prentice Hall, Englewood Cliffs, New Jersey, 1979)

Self-help book which assesses contributors to depression and includes activities, relaxation techniques, thinking, social skills, self-control, and specific ideas and exercises for each problem area.

The Depression Workbook by Mary Ellen Copeland, (Harbinger, 1992)

Assists individuals in taking responsibility for wellness by using charts and techniques to track and control moods. The most complete and useful self help book for bipolar and unipolar depressions.

The Feeling Good Handbook by David Burns, (Penguin, New York, NY, 1989)

Self-help book presents rationale for cognitive therapy for depression. Gives specific ideas and exercises to help change thought patterns associated with depression and other problems.

Lithium and Manic Depression: A Guide by John Bohn and James Jefferson

A very helpful guide for people with manic depression and their families regarding lithium treatment. Order from Lithium Information Center, Department of Psychiatry, University of Wisconsin, 600 Highland Ave., Madison, WI 53792.

Our Special Mom and Our Special Dad by Tootsie Sobkiewicz, (Pittsburgh: Children of Mentally Ill Parents, 1994 and 1996)

Two interactive storybooks that allow primary school age children to understand and identify with the problems associated with having a mentally ill parent. Can be well utilized by a relative or therapist in individual or group work.

Overcoming Depression, Third Edition by D. & J. Papolos, (Harper & Row, 1997)

A comprehensive book written for persons suffering from manic depression and major depression, as well as their families. It is the best source of information about these disorders. Does not offer coping strategies. This book and *The Depression Workbook* are the best two to read.

An Unquiet Mind by Kay Redfield Jamison

A compelling and emotional account of the author's awareness, denial, and acceptance of her bipolar disorder. It offers hope for recovery to anyone who reads it.

Books on Dual Diagnosis (Mental Illness and Substance Abuse)

Alcohol, Street Drugs, and Emotional Problems: What You Need to Know by B. Pepper and H. Ryglewicz

These informative pamphlets come in versions for the client, for the family and for professionals. They can be ordered from TIE Lines, 20 Squadron Blvd. Suite 400, New York, NY 10956.

Lives at Risk: Understanding and Treating Young People with Dual Disorders by B. Pepper and H. Ryglewicz

Poignant description of the combination of schizophrenia, mood disorders, and/or personality disorders with substance abuse. Strong on empathy and understanding of the multiple problems. Provides little specific guidance.

Hazelden Publications. RW9 P.O. Box 176, Center City, MN 55012-0176 Phone 1-800-328-9000 or Website www.htbookplace.org

htbookplace.org

Publishes a large number of pamphlets and self-help books on substance abuse and dual diagnoses. Examples of titles include:

- **Preventing Relapse Workbook**
- **Taking Care of Yourself: When a family member has a dual diagnosis**
- **Twelve Steps and Dual Disorders**
- **Understanding Schizophrenia and Addiction**

Books about Children who have a Mental Illness

Children and Adolescents with Mental Illness: A Parents Guide by E. McElroy, (Woodbine House, 1988)

Useful guide written by a psychologist who heads the NAMI Children's and Adolescent network.

Educational Rights of Children with Disorders: A Primer for Advocates by Center for Law and Education, (Cambridge 1991)

Neurobiological Disorders in Children and Adolescents by E. Peschel, R. Peschel and C. Howe, (Oxford Press, 1992)

Biological mental illnesses among children are less common and less understood "family problems". This book helps to define childhood neurobiological disorders and gives guidance for finding appropriate treatment.

Books on Special Topics

Planning for the Future and the Life Planning Workbook by L. Mark Russell and Arnold Grant, (American Publishing Company, 1995)

This book and accompanying workbook are guides for parents seeking to provide for the future security and happiness of an adult child with a disability following the parents' deaths.

A Parent's Guide to Wills and Trusts by Don Silver, (Adams-Hall, 1992)

Information on how to protect a disabled child's financial future, written by an attorney and NAMI member.

Schizophrenia and Genetic Risks by Irving Gottesman

This pamphlet contains detailed information about this single topic. It may be ordered from NAMI.

A Street is Not a Home: Solving American's Homeless Dilemma by Robert Coates, (Prometheus, 1990)

Analysis and guide to dealing with homelessness among persons suffering from mental illness.

Suicide Survivors: A Guide for Those Left Behind by Adina Wroblewski, (Afterwards, 1991)

With an understanding attitude, explores and offers coping suggestions for the many issues that confront families who have had a member commit suicide.

Reading List for Families with a Member who has a Mental Illness

(Annotations by Christopher S. Amenson, Ph.D.)

Books which offer Guidance to Families

Coping with Schizophrenia: A Guide for Families by Kim Mueser and Susan Gingerich, (New Harbinger, 1994)

Comprehensive guide to living with schizophrenia and the best source for practical advice on topics including medication, preventing relapse, communication, family rules, drug use, and planning for the future. Includes forms and worksheets for solving typical problems.

Schizophrenia: Straight Talk for Families and Friends by Maryellen Walsh, (Morrow & Co., 1985)

This book is written by a parent who, as a professional writer, thoroughly researched the field. This book is emotional in ways that will touch you and deals with all the issues important to families of persons of schizophrenia. If you can read only one book, select this one if you want to feel understood; select *Understanding Schizophrenia* to access current research on causes and treatments; select *Coping with Schizophrenia* if you want concrete advice about coping with the illness.

Surviving Schizophrenia: A Family Manual, Third Edition by E. Fuller Torrey, (Harper & Row, 1995)

Beloved by the Alliance for the Mentally Ill because it was the first book in 1983 to support and educate families. Contains one of the best descriptions of "The Inner World of Madness". Discusses the major topics in easy to read and very pro-family language.

Troubled Journey: Coming to Terms with the Mental Illness of a Sibling or Parent by Diane Marsh and Rex Dickens, (Tarcher/Putnam, 1997)

The best book for siblings and adult children. Helps to recognize and resolve the impact of mental illness on childhood. Seeks to renew self-esteem and improve current family and other relationships.

Understanding Schizophrenia: A Guide to the New Research on Causes and Treatment by Richard Keefe and Philip Harvey, (The Free Press, 1994)

The best description of research on schizophrenia as of 1994. It provides more depth and detail than *Surviving Schizophrenia* and is a little more difficult to read. A must for families that want to understand the science of schizophrenia.

How to Live with a Mentally Ill Person: A Handbook of Day-to-Day Strategies by Christine Adamec, (John Wiley and Sons, 1996)

This comprehensive, easy-to-read book is written by a parent. It reviews methods for accepting the illness, dealing with life issues, developing coping strategies, negotiating the mental health system, and more.

Books describing the Experience of Schizophrenia

Anguished Voices: Siblings and Adult Children of Persons with Psychiatric Disabilities by Rex Dickens and Diane Marsh, (Center for Psychiatric Rehabilitation, 1994)

Collection of 8 well-written articles which describe the impact of mental illness on siblings and children. A poignant statement of the issues across the life span that need to be addressed when a person grows up with mental illness in the family.

Crazy Quilt by Jocelyn Riley, (William Morrow, 1984)

Fictional account of a 13-year-old girl whose mother has schizophrenia. Written for children and adolescents. Provides understanding for these forgotten individuals.

Is There No Place on Earth for Me? by Susan Sheehan, (Houghton-Mifflin, 1982)

A very realistic depiction of the experience of a schizophrenic woman is interwoven with information about legal, funding, and treatment issues. Gives a good description of historical and political influences on the treatment of persons suffering from schizophrenia. Won the Pulitzer Prize.

Tell Me I'm Here: One Family's Experience with Schizophrenia by Ann Devesch, (Penguin, 1992)

Written by a United Nations Media Peace Prize winner and founder of Schizophrenia Australia, this book describes her family's experience.

The Quiet Room by Lori Schiller, (1994)

The life story of a person who had an almost full recovery from schizophrenia with clozapine. Great for its inspirational value. Only one in a thousand clients recover to this degree.

The Skipping Stone: Ripple Effects of Mental Illness on the Family by Mona Wasow, (Science and Behavior Books, 1995)

Describes the impact of mental illness on each member of the family in a "Tower of Babel".

The Girl with the Crazy Brother by Betty Hyland, (Franklin Watts, 1986)

Written for adolescents by an Alliance for the Mentally Ill member.

Website Resources

Schizophrenia

www.schizophrenia.com

Bipolar Disorder

www.mhsource.com/bipolar

www.bpkids.org

NAMI

www.nami.org

www.nami.org/helpline/peoplew.htm (well-known people with mental illnesses)

Government Sites

www.samhsa.gov/cmhs

www.nimh.nih.gov

Professional Organizations/Publications

Most valuable for schizophrenia information of high quality from peer-reviewed journals would be the American Psychiatric Association's site: www.psych.org

Multi-specialty site cooperating with APA: www.medem.com

www.rcpsych.ac.uk/info (Psychological approaches to psychosis)

Early Intervention with Psychosis

www.iepa.org.au (International Early Psychosis Association)

Antistigma

www.adscenter.org

Stress and Drug Abuse

www.nida.nih.gov/DrugPages/Stress.html

Special Populations Appendix

A review of the literature addressing the range of populations for which family psychoeducation has demonstrated efficacy or effectiveness, including factors such as age, race, ethnicity, gender, diagnosis, nationality, institutional setting, sexual orientation, and rural or urban location.

The most consistent finding from the family psychoeducation (FPE) literature has been the absence of specific client factors predicting better outcomes. Diagnosis may be the closest to a specific indicator, but that is primarily because there are fewer published studies of outcomes for diagnoses other than schizophrenia. Specifically, symptomatology, age, gender, disability status, prior hospitalization, duration of illness and education have been examined and none have proven to be strong or consistent predictors. Family expressed emotion at baseline has proven to predict outcome within studies of treatment effects, as it has in studies without intervention (1, 2). However, Falloon showed that outcome was better predicted by coping skill improvements in treatment for family members (3).

At present, FPE has been shown to be most effective for individuals diagnosed with schizophrenia. There have been at least 20 controlled trials, involving nearly 5000 consumers and their families, and two are underway in Scandinavia that will involve nearly 1000 consumers and their families. Outcome has been remarkably consistent across all but two of the published clinical trials (4, 5). For that reason, schizophrenia is the principal diagnostic focus of this toolkit. Briefly described within the Workbook, modifications have been developed and tested for bipolar disorder (6, 7), depression (8), borderline personality disorder (9) and OCD (10). Multifamily group versions for these disorders have recently been described in *Multifamily Groups in the Treatment of Severe Psychiatric Disorders* (11). Single-family versions have been tested and found to be effective for bipolar disorder, and studies are underway for the other disorders.

Within-study comparisons of relapse rates for different ethnic groups have led to at least one set of indications, in this case for multi- or single-family formats. One of the U.S. studies was a large, multisite effectiveness study conducted in state- or city-operated clinics and hospitals, in which multifamily groups had significantly lower (by about 1/3) relapse rates in five of the six sites (12). This study also identified a subgroup for which the single-family format was *more* effective – African-American families with low expressed emotion and patients with unusually good response to medication during the index hospitalization (13). First-episode cases, regardless of other characteristics or ethnicity, did substantially better in multifamily group than in single-family sessions, a counter-intuitive finding, but one that was significant (13).

Randomized controlled trials of family psychoeducation have been conducted in settings and other countries in which there were significant numbers of Caucasian, African-American, Asian

and Latino subjects. Earlier studies have been conducted in London (14-16), Pittsburgh (2), New York City (17), New York State (12), Los Angeles (1, 18), Philadelphia (19), Atlanta (19), New Jersey (20), and China (21, 22) and others. Recent studies in Spain (23-25), China (26-29), Scandinavia (30), Japan (submitted) and the U.K. (31) have demonstrated the same robust effects as in prior studies in English-speaking and other countries. That these effects are additive to, but not substitutive for, antipsychotic medication was illustrated in a recent German study (32).

The one exception to generalized effectiveness was noted in a study by Telles and colleagues in Los Angeles, in a Spanish-speaking immigrant sample (5). There was a reversed effect for behavioral family management (using a single-family format) among those from a less acculturated subgroup and no effect for those from the more acculturated subgroup. It appeared that the Los Angeles sample's immigrant status may have negated the effects of family intervention. At present, a study is underway testing the efficacy of psychoeducational multifamily groups in Latino people. Though early indications are much more positive than in the prior single-family study, final conclusions need to await outcome analysis.

Although more replications are desirable, all the evidence to date suggests that the effectiveness of family psychoeducation compared to conventional individual therapy generalizes to nearly all major cultural populations: British-American and Australian, African-American, Spanish/Latino, Scandinavian/Northern European, Chinese and Japanese. On the other hand, anecdotally, we know that culture and language pose significant barriers to providing family psychoeducation in some populations and, in any case, require culturally sensitive adaptations and need to be further explored empirically.

Some client factors have not been systematically examined in the literature. For example, we know of no studies that have examined sexual orientation and how that might affect outcomes in family psychoeducation programs.

Community characteristics do not appear to impose a major barrier to implementing this approach. Family psychoeducation has been successfully implemented in both very urban and very rural settings, as well as in mid-sized cities and suburbs. Ironically, some of the most impressive outcomes have occurred among minority members of distressed and poverty-stricken urban populations (1, 12, 19). Many different states have implemented the model (33-35).

Nearly all of the controlled research on effectiveness has been conducted in outpatient clinics and community mental health centers, beginning treatment in several studies during an inpatient hospital stay. The multifamily group model was developed in a partial hospital in the South Bronx of New York City. The extent to which family psychoeducation can be successfully adapted to other types of provider agencies is not known. Ranz and colleagues developed an adaptation for application in community residences, *with or without* family participation, that appeared to alleviate stresses within the residences and improved outcomes, but a rigorous trial of this approach has not been completed (36).

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